



THE UNIVERSITY *of* EDINBURGH

Edinburgh Research Explorer

What is the point of citizen participation in health-care?

Citation for published version:

Stewart, E 2013, 'What is the point of citizen participation in health-care?', *Journal of Health Services Research & Policy*, vol. 18, no. 2. <https://doi.org/10.1177/1355819613485670>

Digital Object Identifier (DOI):

[10.1177/1355819613485670](https://doi.org/10.1177/1355819613485670)

Link:

[Link to publication record in Edinburgh Research Explorer](#)

Document Version:

Peer reviewed version

Published In:

Journal of Health Services Research & Policy

Publisher Rights Statement:

© Stewart, E. (2013). What is the point of citizen participation in health-care?. Journal of Health Services Research and Policy, 18(2).

General rights

Copyright for the publications made accessible via the Edinburgh Research Explorer is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy

The University of Edinburgh has made every reasonable effort to ensure that Edinburgh Research Explorer content complies with UK legislation. If you believe that the public display of this file breaches copyright please contact openaccess@ed.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.



What is the point of citizen participation in health care?

Ellen A Stewart

School of Social and Political Science, University of Edinburgh, Edinburgh

Abstract

Does citizen participation in health care planning and provision have a clear purpose? Can it reasonably be considered a unified phenomenon? Current conceptual accounts – including a range of typologies descended from Arnstein’s ubiquitous but misunderstood ‘ladder of participation’ – are inadequate. The popularity of citizen participation belies fundamental uncertainties about what it entails and its associated benefits. A more pragmatic and less normative usage of the term is vital for the future.

Participation has been a central if indistinct part of our understanding of good health care since at least the WHO’s Alma Ata declaration, which stated “The people have a right and duty to participate individually and collectively in the planning and implementation of their health care”.¹ Since then an industry of commentators and practitioners has emerged.

However, disagreements about the basics of participation remain unresolved and frequently unaddressed. In current practice, staffing public education stalls, attending presentations on car parking and filling in surveys on patient experience are seen as participatory acts,² yet the rhetoric of participation remains rooted in power and conflict. Does participation in health care have a clear purpose and can it be considered a unified phenomenon?

Introducing participation

While the concept of participation is widely recognised as difficult,⁴⁻⁶ literature on participation in health care has continued to grow apace. One result of this is a remarkable

degree of terminological instability. Debate revolves around a range of terms formed by adding a named group of participants ('public' 'patient' 'citizen' 'community' or 'user') to a type of activity ('involvement' 'engagement' or 'participation'). This is not merely semantic but denotes disagreement about the nature and purposes of participation.

Attempts to define participation in health care end up unworkably vague. For example, Tritter's effort to conceptualise 'public and patient involvement' (the preferred term in the English NHS since the late 1990s), ranges from direct public decision-making to the gathering of patients' views on everything from individual treatment decisions to the training of health professionals.⁶ It seems that almost any health care activity involving a conscious patient or citizen can be understood through the lens of participation. Tritter seeks to contrast public and patient involvement with patient choice but even this is not obviously excluded from the definition he offers: "Ways in which patients can draw on their experience and members of the public can apply their priorities to the evaluation, development, organization and delivery of health services".⁶

Tritter is not alone in struggling to produce a workable definition of participation.

Abandoning the search for a catch-all description, numerous authors have turned instead to a system of classifications to deal with the vast range of initiatives that profess to be 'participation'.^{3, 7-10} These typologies emphasise the degree of power gained by citizens, the public, or specific service users. Existing typologies can be mapped against each other and, even where the label used differs, the content of each 'level' of participation is reasonably consistent. However, in a demonstration of the risks of a literature emerging without a solid conceptual grounding, over time typological levels have tended not just to reduce in number but to concentrate in the middle of the ladder. Arnstein's original 'ladder of participation' ran

from citizen control to the bottom rungs of manipulation and ‘therapy’ (an interesting inclusion given the trend for participatory initiatives to be sold as producing more informed and responsible service users). More recent literature ignores these provocative possibilities and presents instead a technical ‘menu’ of approaches. In this way, typologies of participation have become less radical over time and have diluted Arnstein’s highly critical account.

Why should participation be a priority for health systems?

In health care systems, potential (claimed) benefits for citizen participation range from accountability for public funds, medical rationales for responsiveness (incorporating the plethora of potential gains from a ‘co-production’ approach), consumeristic objectives of service efficiency, better informed (and implicitly more ‘responsible’) service users, and mutual support for service users. Bochel and colleagues’ review of the benefits of participation argued that: “participation might be intended to improve governance, democracy, social capital, education and development of individuals, policies, service implementation and delivery – all, or one or more of these, or something else altogether” ¹¹. In short, participation is presented as offering better services, better outcomes and better service users. The authors nonetheless conclude by re-stating their commitment to the possibility of “real” participation: like Tritter ⁶, they evidently operate with a tacit understanding of the purposes of participation and yet a clear statement of these is not offered.

Harrison and colleagues¹⁰ depict three versions of participation in health care: consumerist, democratic and ‘New Social Movement’ (an emancipatory concern with vulnerable or marginalised sections of society). These can be understood as groupings which reflect deeper divisions in approach and purpose. The concerns of (consumeristic) public management

scholars are often rooted in organisational effectiveness, which is assumed to be a broadly straightforward (and objectively determinable) goal: as long as *someone* is voicing concerns about an organisation, it is not of great concern whether they are representative of the wider population.

Researchers working from the perspective of New Social Movements would likely dispute this. For these researchers, the lessons of the disability movement and other user groups are that mainstream preferences for an organisation can be profoundly at odds with what some of the most vulnerable sections of the population need.¹² Arnstein's arguments, built from a concern with society's 'have nots', fall into this category and, when next we cite her ladder of participation, we should do so with awareness of the particular radical perspective which has made this work so widely known and so poorly understood.³ Finally, for scholars concerned with an overarching picture of democracy, rather than a primary emphasis on vulnerable groups, concerns are about "the fundamental democratic tests of popular control and political equality".¹³

While good analysis may produce a clearer specification of participation, this would require academics, policy-makers and practitioners to agree on what they understand as participation in health care. Alternatively, participation can be seen as "a descriptive umbrella term for the spectrum of processes and activities that bring the public into the decision-making process"⁴. While this might sacrifice the aura of righteousness which currently surrounds participation, there are advantages to acknowledging the range of participatory activities and rationales, accepting differences and being clear about them.

Conclusion

The persistent yet ill-specified normative appeal of participation in health care is undermined by a lack of conceptual foundation. The lack of specification of participation allows policy-makers, practitioners and researchers to go about their business without having to resolve the uncertainties and conflicts contained within the phenomenon, or to choose between the democratic, consumeristic or emancipatory rationales discussed above.

Abandoning the idea that participation in health care denotes a self-evident (and self-evidently commendable) set of activities requires us to be much clearer about the purposes of participatory activities and the standards by which we judge them. Doing so will force us to acknowledge the changes in emphasis which can be identified over time. Incoherent definitions have facilitated the growth of both literature and policy on public participation in health care. It is time to admit that participation rationales are far from self-evident and accept that participation is a site of disagreement, rather than an unqualified good.

1. World Health Organisation. Declaration of Alma-Ata. International Conference on Primary Health Care. Alma-Ata, USSR; 1978.
2. [The author]. Governance, participation and avoidance: everyday public involvement in the Scottish NHS. Edinburgh: University of Edinburgh, 2012.
3. Arnstein SR. A ladder of citizen participation. *Journal of the American Institute of Planners*. 1969; **35**: 216-24.
4. Conklin A, Morris ZS, Nolte E. Involving the public in healthcare policy: an update of the research evidence and proposed evaluation framework. Cambridge: RAND Europe; 2010.
5. Crawford MJ, Rutter D, Manley C, Weaver T, Bhui K, Fulop N, et al. Systematic review of involving patients in the planning and development of health care. *British Medical Journal*. 2002; **325**.
6. Tritter JQ. Revolution or evolution: the challenges of conceptualising patient and public involvement in a consumerist world. *Health Expectations*. 2009; **12**: 275-87.
7. Feingold E. Citizen participation: a review of the issues. In: Rosen H, Levey S,

Metsch J, (eds.) *The consumer and the health care system: social and managerial perspectives*. New York: Spectrum Publications, 1977.

8. Charles C, Di Maio S. Lay participation in health care decision making: A conceptual framework. *Journal of Health Politics, Policy and Law*. 1993; **18**.
9. Thompson AGH. The meaning of patient involvement and participation in health care consultations: A taxonomy. *Social Science & Medicine*. 2007; **64**: 1297-310.
10. Harrison S, Dowswell G, Milewa T. Guest editorial: public and user 'involvement' in the UK National Health Service. *Health & Social Care in the Community*. 2002; **10**: 63-6.
11. Bochel C, Bochel H, Somerville P, Worley C. Marginalised or enabled voices? 'User participation' in policy and practice. *Social Policy & Society*. 2008; **7**.
12. Barnes M. Whose spaces? Contestations and negotiations in health and community regeneration fora in the UK. In: Cornwall A, Coelho VSP, (eds.) *Spaces for change? : the politics of citizen participation in new democratic arenas*. London: Zed, 2007.
13. Lowndes V, Pratchett L, Stoker G. Trends in Public Participation: Part 2 – Citizens' Perspectives. *Public Administration*. 2001; **79**: 445-55.